The Patient Care Component: Patient-Centered Horizontal Integration in a Vertical World

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This paper describes the structure and operational properties of the Patient Care Component, a patient care data system developed by the Indian Health Service to support primary care in a multi-site, decentralized, health care organization. Sharing the same technology base as the Department of Veterans Affairs Distributed Hospital Computer Program, the system requires a minimal level of investment in technology compared to alternative approaches and is in operation at 140 sites. The Indian Health Service and historical aspects of the system are described briefly; the paper focuses on the design objectives for the system and lessons learned from development and several years of operational experience.

BACKGROUND

The Indian Health Service (IHS) is part of the U. S. Department of Health and Human Services and is, like the National Institutes of Health and the Centers for Disease Control, an agency of the U. S. Public Health Service. It is responsible for providing comprehensive health care to approximately 1.2 million American Indians and Alaskan Natives, often from birth to death, in rural and generally remote regions of the country. This is accomplished through a system of IHS direct care facilities (47 hospitals and 122 outpatient centers), IHS-funded tribal programs (another 7 hospitals and 149 outpatient sites), and services contracted for from the private sector. The organization has approximately 15,000 employees and a budget of about 1.7 billion dollars. Its programs range from installation of basic sanitation infrastructure, such as water and sewer systems, to dental and medical care delivered in facilities, communities, schools, and homes.

Efforts to bring information systems support to primary care in the IHS began in 1968 with development of the Health Information System (HIS), which used clinically-oriented encounter forms to capture a wide range of patient data in ambulatory care settings. The HIS was mainframe-based, written in COBOL, and did not use a database management system (DBMS). A later version, the Patient Care Information System (PCIS) [1,2], expanded on the HIS while retaining its essential nature. These systems eventually served the Sells Service Unit (in Southern Arizona) in an on-line mode, and the Billings (Montana) and Alaska Areas through microfiche. While advanced for their time, their reliance on mainframe and non-DBMS technology made the HIS and PCIS too expensive and inflexible to be attractive for widespread implementation, and constant targets for cutbacks.

In 1983, the IHS decided to decentralize its information systems to deliver computing capacity and control of data management to points of patient care and program management in the field. As a result of previous experience, vendor independence and portability across hardware platforms were major considerations. At the same time, there was considerable pressure on IHS by its parent agencies to purchase commercial systems for cost accounting and any clinical applications. During the market survey carried out in response to these directives, which was markedly unsuccessful, IHS became aware of the Department of Veterans Affairs Distributed Hospital Computer Program (DHCP). In 1984, the IHS decided to adopt DHCP's underlying technology as the basis for development of the Resource and Patient Management System (RPMS) and to make selective use of DHCP applications while converting clinical applications such as the PCIS (as the Patient Care Component, or PCC) to operate in the DHCP setting to support ambulatory and longitudinal care.

This paper presents experience with implementing PCC as a patient-centered data system and introducing PCC into the DHCP as a vehicle for integration of data from vertical applications.

THE VA DISTRIBUTED HOSPITAL COMPUTER PROGRAM

With 171 medical centers, approximately 200,000 employees, and a budget for medical programs of some 12.5 billion dollars, the Veteran's Health Administration is a large operation by any standard. Its major information system is the DHCP, whose basic goal is to provide automation support for both clinical and administrative activities. Historically, despite significant opposition from the commercial sector, emphasis has been placed on:

- Self-directed evolution, in-house development, and dedication to user-driven specification and design.
- A high degree of vendor independence and platform portability.

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- Standardization in the areas of programming language (MUMPS), data exchange protocols (HL7), and graphics standards (X-Windows)

These considerations have had significant impact on every phase of DHCP, from application design through hardware and software procurement.

Initial DHCP releases focused on rapid-payoff vertical departmental applications. Now, more than ten years after its inception, DHCP is beginning to provide direct support for front-line providers. Applications in this category include ones developed *de novo* by the VA as well as ones which borrow from their IHS counterparts. The infrastructure provided by existing, widely deployed, departmental systems is an asset.

A strong technology focus differentiates the VA's approach to computational support for patient care from that of the IHS. Major initiatives currently underway across the VA system include imaging, intelligent workstations, and point-of-care data collection and verification. These have significant implications both in terms of resource requirements and impact on future application design strategies. In addition, the VA explicitly espouses the goal of a complete electronic medical record.

THE IHS PATIENT CARE COMPONENT

The PCC is a product of a mixed heritage, melding functional attributes of its predecessor, PCIS, and technology drawn from the DHCP. Its objectives are surprisingly similar to those set down twenty-five years ago, although the circumstances of implementation have changed dramatically.

Common barriers to the delivery of comprehensive health care faced by the IHS include:

- Patient mobility, partly as a result of a hierarchy of health care facilities.
- Distance to health care, and the related opportunity cost of not taking full advantage of the patient's visit.
- Limited time with the patient, perhaps as little as six to ten minutes.
- Provider turnover, typically on the average of every two to five years.
- Difficulty of keeping track of periodically performed tasks.

As a consequence of these motivators, the goals of the PCC are to:

- Support providers of front-line primary care with generic capabilities as well as specialty-oriented applications.
- Meet the comprehensive needs of longitudinal care and ambulatory settings.
- Integrate patient data from multiple disciplines and sources, even across sites.
- Record core aspects of every encounter of a patient with the health care system, whether services are provided directly or through external contracts.
- Provide managerial and administrative data as a byproduct of the patient care process.

Clinical data systems have developed in the IHS primarily as a result of grass roots interest rather than through top-down management direction or as a follow-on to the automation of ancillary systems. Thus, the PCC evolved in a climate which emphasized ways to improve the quality and effectiveness of direct patient care in a setting characterized by small rural sites, a mobile patient population, and community-based public health.

From an organizational perspective, this has meant establishing design guidelines and operational policies which emphasize:

- Independence of clinical data from data management policies of ancillary departments.
- Accommodation of data originating outside the site.
- Patient-centered data organization.
- Access to data along multiple axes.
- Minimizing ownership and control issues characteristic of vertical applications.

To date, the IHS has not aspired to a complete electronic record, viewing the PCC as a summary and index of the traditional record rather than an eventual replacement; this has had a strong influence on application design. However, major emphasis is placed on PCC's role as a focal point for communication and data sharing among members of the health care team, even in the face of security and confidentiality constraints.

The IHS has had to approach the development of information systems in general, and medical systems specifically, from a much lower level of technology than the VA. Beyond geographical remoteness of facilities, as well as a generally lower level of resources for development of computing infrastructure, this is a reflection of the disparity in size of facilities, a consequently lower level of clinical services offered, and extraordinary difficulty in recruiting and retaining competent IRM staff. While working toward increased sophistication in the long run, IHS has traditionally had to develop less technology-intensive approaches to problems such as data capture in ambulatory care settings (e.g., using clinically-oriented encounter forms rather than direct provider-system interaction).

THE PCC AS A FOCUS FOR PATIENT-CENTERED DATA INTEGRATION

Technical integration

PCC was designed specifically to integrate tightly with DHCP. This relationship is represented schematically in Figure 1, which illustrates major PCC and DHCP files (squared and rounded rectangles, respectively) and the sharing of core DHCP files (patient file, drug file, etc.) by PCC through pointer linkages. As can be seen, the PCC file structure is patient- and visit-centered, and designed for ease of access along axes of patient, visit, time, or class of data. For example, the patient-specific Health Summary follows links from patient file to data file, population-based epidemiological reports follow links from visits to data, and program-specific reports (such as immunization statistics) focus on individual data files. The flat, normalized structure combines aspects of both relational and network database models, and simplifies addition of new data classes.

Like all RPMS applications, PCC relies on the VA Kernel for services such as database management, menuing, messaging, etc. Unlike another notable comprehensive system, the Department of Defense Composite Health Care System (CHCS), RPMS and PCC are designed specifically to coexist with DHCP. This has made it possible to attempt bi-directional transfer of technology between IHS and VA [3]. The PCC is currently in test at the VA medical center in Tucson, and has required only minimal adaptation to cope with VA-specific health care practices.

Operational integration

In operation, the PCC supports three major types of integration:

Cross-application As shown in Figure 2, the PCC receives data from a number of sources, including active links from both VA and IHS applications (e.g., lab, pharmacy), entry of encounter form data supplied by providers, and automated external data sources. This repository structure isolates clinical data from dependencies on data management policies of ancillary systems and provides the ability to store data arising from other sites without contaminating data used for workload measurement, etc. in ancillary packages. In addition, it allows generic tools, such as the PCC query manager (QMAN) and the clinical reminder system to access data without issues of ownership or complex data structures [4].

Cross-discipline Health care in the IHS is truly a multi-disciplinary activity, involving a spectrum of staff including physicians, nurses, community health workers, etc. The PCC is the team's system, rather than a "physician's system" or a "nurse's system".

Cross-facility As noted above, the PCC database houses patient care data regardless of the site at which it was delivered. This has been exploited in the IHS multi-facility integration project (MFI).[5], which uses electronic mail to route transactions reflecting clinical activity and alteration of demographic data to all sites at which the patient has records.

Achievements

Resources for formal evaluation of PCC have been non-existent. However, outcomes observed as a result of site reports and surveys of provider perceptions include improvements in:

- integration of patient information across sources;
- communication among health care team members;
- follow-up of high-risk patients;
- provision of preventive services;
- performance of tasks related to chronic conditions.

The PCC has proven its value in production use as a system which is patient centered from the perspective of front-line providers, but which is simultaneously capable of supporting views of the database focused on cohorts or selected data classes for purposes of quality assurance and program management. Beyond its clinical roles, PCC has replaced earlier statistical data collection systems with clinically-relevant data capture, and now provides the basis for third-party billing -- an increasingly important aspect of patient care in the current fiscal climate.

FUTURE CHALLENGES

To remain a long-term success, the PCC must successfully address a number of critical issues:

- requirements for storage of additional types of data as interests and priorities change -- e.g., health status and risk factors, radiology, microbiology.
- requirements for new modes of integration with specialty systems -- e.g., maternal and child health, which imposes a strong programmatic framework on a constellation of independent classes of data (such as procedures, anatomic path, and pharmacy).
- incorporation of decision support capabilities -- e.g., enhanced clinical reminders and surveillance, which entails development of more powerful inferencing facilities with tighter integration into mechanisms through which data enters the system.
- complexities of inter-site data exchange -- e.g., inter-facility transfer, and installation in the database, of patient data; for IHS this currently means adaptation of the MFI project to HL7 as a part of working with the VA.
- position and funding limitations impacting the use of clerical-based data entry, which may dictate shifting data entry workload to clinicians.

The common factor underlying all of these matters is the requirement to adapt to changing circumstances. This need for flexibility was anticipated early on, and PCC was designed with an open architecture. This has enabled it to accommodate changes such as the recent addition of microbiology results, tests in a live DHCP environment at a VA medical center, and -- perhaps the ultimate role shift -- use as a "patient" information system in a veterinary school!

CONCLUSIONS

The PCC has been in operation in the IHS for six years, expanding from the initial sites of development and testing to support daily patient care at some 220 hospitals and clinics; in fiscal year 1993 (the most recent period for which statistics are available) approximately 2,912,500 ambulatory visits were recorded in PCC at 85 IHS direct care sites. For contrast, the Tucson VA medical center pilot project captured data at that single facility from some 186,200 visits in PCC in the twelve months beginning February 1993. The system has also had an impact outside IHS: it is the basis of the VA's PCE (Patient Care Encounter) application, now in the early stages of release within the VA DHCP system. PCC forms the outpatient component of the hospital system of Saipan, and has informally been reported to be in operation as far away as Siberia.

The PCC and its predecessor systems represent a quarter-century of experience in pragmatic support of primary care providers in busy, low-technology, ambulatory care settings. Many of the lessons learned can be distilled into three observations:

1. It's more important to first establish an appropriate repository for clinical data (i.e., in terms of data representation and scope) than to expend significant resources on developing sophisticated approaches to data capture. While the latter is a necessity in the long run, operational success and clinical acceptance is impossible without functional relevance to care providers, and that is primarily an outcome of managing data which is useful in direct patient care.

2. It's vital to avoid "analysis paralysis" and get systems into the field where real-world experience can be used to test acceptance and define the need for future enhancements. This is particularly true in large, multi-site organizations where practical limitations on large scale testing are bound to bias initial designs.

3. It's easier to talk about integration than to achieve it (or "Integration is fine as long as I don't have to do anything"). In addition to workable technical approaches, a mind set is required which places high value on integration of information systems -- as well as their intimate involvement in the health care process, to the ultimate benefit of the patient -- and accepts the necessity of cooperation from the numerous groups of interest which comprise the medical milieu. This mind set has to be fostered in development centers, ancillary services, and (ironically) the provider community.

Despite its "school of hard knocks" flavor, the PCC experience provides evidence that technology integration can be successful given the right circumstances, and that an integrated, patient-centered clinical database can play an important role in an environment of sophisticated vertical applications.

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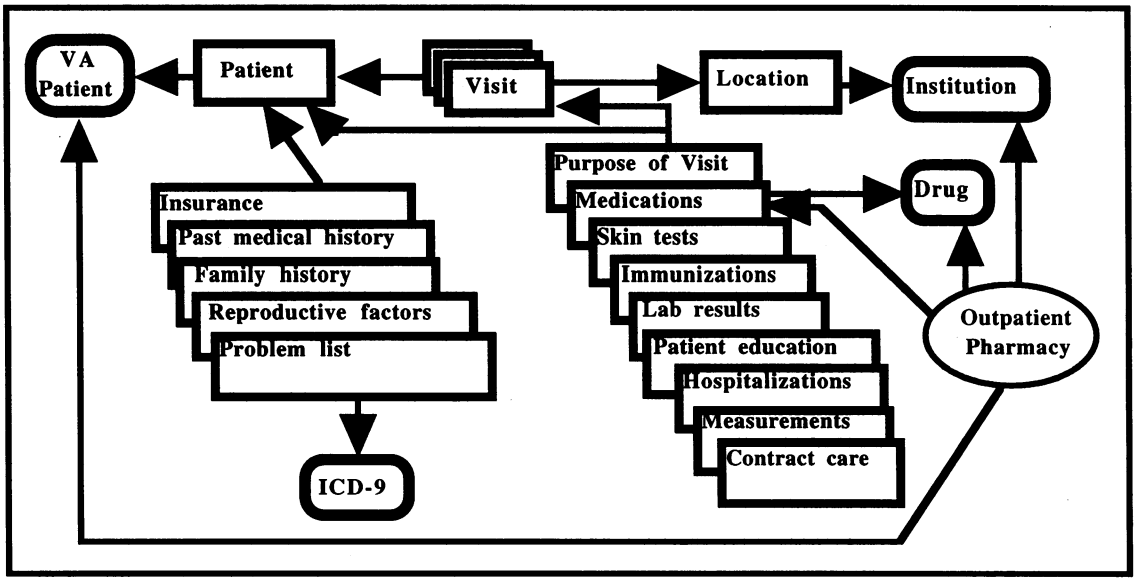

Figure 1
Relationship of PCC and DHCP

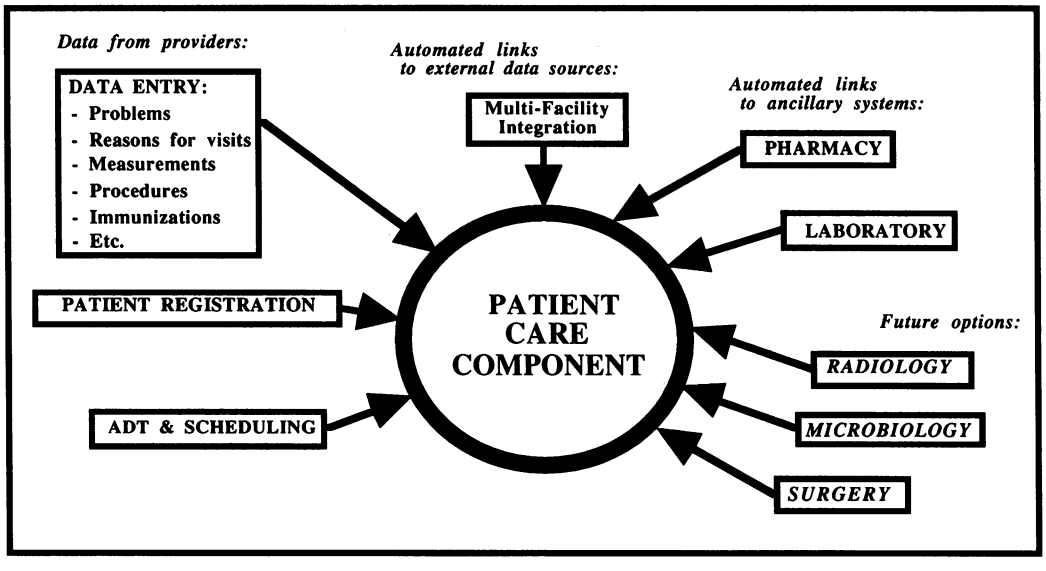

Figure 2
PCC as an integrating focus